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Evaluating a Community Interdisciplinary Neurological Rehabilitation Team using patient interviews focused on self-management

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Abstract

The Planned Rehabilitation Team is a Community Interdisciplinary Neurological Rehabilitation Team (CINHRT) in the South-West, providing rehabilitation for adults who have Long Term Neurological Conditions such as Multiple Sclerosis and Motor Neuron Disease. The service aims to help develop service users' ability to self-manage their condition and become more independent by providing rehabilitation in their homes and local community. This paper reports an evaluation of the service via service-user interviews with individuals who have a long-term progressive neurological condition. The data, alongside a literature review and clinician feedback, were then used to develop recommendations about information provision, staff training and service protocols, which may be applicable to other similar teams.

Introduction

Long-term neurological conditions (LTNCs) are those in which there is disease or injury to the nervous system and are life-long. They affect an estimated 10 million people in the UK (National Guidelines for Long-term Neurological Conditions, 2005). It is estimated that around 350,000 of these people need help with daily living tasks

(The Neurological Alliance, 2019). Having a LTNC can affect an individual's physical and mental health and as a result significantly impact an individual's overall quality of life (The Neurological Alliance, 2014).

Self-management of LTNCs is a key principle outlined within government policy for chronic disease management (Department of Health, 2010). The 'promotion of self-care' is also included within the National Service Framework for LTNCs, which sets quality standards for supporting this population (Department of Health, 2005). Further guidance has been developed in helping professionals to support service-users to self-manage (Battersby et al., 2010). However, as highlighted by Barlow et al (2002) in their review of self-management approaches for people with chronic conditions, there is no 'gold standard definition of self-management'. For example, Alderson et al (1999) refer to self-management as 'inter-disciplinary group education, based on the principles of adult learning, individualised treatment and case management theory', whilst Nakagawa-Kogel et al (1998) describe it as a treatment that combines biological, psychological and social intervention techniques, with a goal of maximal functioning of regulatory processes. For the purpose of this study, self-management was defined as:

"The individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition" (Barlow et al., 2002, p.78).

Our CINHRT provides interdisciplinary support to help people maintain their independence through provision of assistance within areas such as: mobility, home accessibility, wellbeing, cognitive issues and communication. This paper describes a service evaluation of CINHRT from the service-user perspective. The evaluation aimed to explore and understand the experience of individuals LTNCs and their relationship with the service and self-management. The primary aims of the study were to: (1) explore service-user experience of self-management and the impact of the service upon this (2) evaluate the service from a service-user perspective, exploring what is going well and any areas for improvement (3) using evaluation data, alongside existing literature and clinician consultation to inform recommendations and an action plan to improve the current service offered.

Method

The service

The CINHRT team evaluated is based in the South of England and delivers care to individuals with LTNCs living in a small city and the rural surrounding areas. The service is comprised of an interdisciplinary team, consisting of occupational therapy, physiotherapy, speech and language therapy, clinical neuropsychology alongside therapy assistants and administrative support.

Participants

Participants in the study met the following inclusion criteria: living with a long-term progressive neurological condition; on the current team caseload; participated in more than six appointments with two or more professionals from the service; and participating in some degree of self-management of their condition. Exclusion criteria were that the service-user: was receiving palliative care; had clinician-rated severe cognitive deficits or limited comprehension ability; or was considered by the clinician to either lack capacity to consent to participate, or likely to become unduly distressed by participating.

From a clinician-identified list of eleven service-users who met the inclusion criteria, verified by a neuropsychologist, nine consented to be contacted and take part in the study. One person was unable to be contacted and another did not want to participate in the study. The total service caseload is 250 people.

Table 1 provides a summary of the key participant demographics for the study. Of note, all but one of the nine participants had MS.

[Insert Table1 near here]

Procedure

Semi-structured interviews were developed based largely on the UK National Service Framework, namely Quality Requirement 1 (QR 1), provision of a "person-centred service", and QR 5 community rehabilitation and support, (Department of

Health, 2005). Interviews were conducted in person at the service-users home and lasted between 30-45 minutes. Interviews were audio recorded, transcribed and anonymised, after which they were deleted. A collection of stem questions (see Table 2) were used to form the topic guide for the interviews, with additional prompts and questions permitted dependent on participant response.

[Insert Table 2 near here]

Analysis

Thematic analysis was used to identify the themes in the transcribed interviews. The six-step thematic analysis processed described by Braun and Clarke (2006) was used to guide this process. A second independent researcher, who was blind to the study aims, checked the reliability of the analysis. This was conducted by asking the independent researcher to categorise a selection of service user quotations into the different themes, dependent on which theme they felt the quotation best fitted to. This selection was then examined to see whether this was in agreement or different to the selection made by the primary researcher. There was substantial agreement between the two raters, $K = 0.802$. Following the reliability analysis further discussion between the raters took place, and themes were refined and finalised.

Ethics

Ethical approval was granted by the University of Bath Psychology Research Ethics Committee. The Local Research and Development (R&D) department of the NHS Trust approved the study deeming it to be a service evaluation and therefore did not require full R&D approval. Informed consent was obtained from all participants. Participants were informed that if they chose not to participate that this would not affect the care they received from the service in any way.

Results

Four key themes emerged from the data; 'Nature of Having a LTNC'; 'Perception of Self & Disability'; 'Evaluation of Service Support' and 'Role of Assistive Devices.'

[Insert Figure 1 near here]

Nature of Having a LTNC

Uncertainty related to my condition

All service-users acknowledged the uncertainty related to having a LTNC. There was a sense that how they felt changed on a daily basis. Individuals spoke of the difficulty had in not knowing whether the symptoms they were experiencing were due to their LTNC or not, 'I have developed a problem with my shoulder…and it's been determined that it's not MS but they can't quite figure out what it is, cause' this isn't MS, but it could be MS but it's not MS' (Service-user 1).

Information the service did provide about their condition was described sometimes to be 'vague' and primarily verbal with some service-users preferring this to be written instead.

Impact on mental health

Service-users described the psychological difficulties of having a LTNC. Particularly how the presenting symptoms of having a LTNC can vary daily and how other people may not be aware of the difficulties which are experienced. 'You don't want it [MS], believe me. But you know you don't look any different' (Service-user 9).

'I take anti-depressants now and they don't make me connect with reality really. And I am not facing up to the fact that it is getting a lot worse…. I don't know what to do with myself' (Service-user 5).

Adjustment and coping

Service-users discussed the process of coping and adjustment. Most described an initial phase of denial and not wanting support from the team. Most of the service-users perceived this to be a stage they had to go through and that the team couldn't do anything differently at this stage to help them. '[Could the service have done anything else to help initially|?} No, I think that was just me really. Just at the time I just didn't want any of it, I just thought I would be alright and then you find out you are not really' (Service-user 8).

Two service-users described a sense the service was not able to support them due their perception of no one being able to meet their current needs, 'I just feel like I have been put out to pasture now' (Service-user 7).

Service-users appeared to struggle with the difficulties of understanding and acknowledging the limitation in their own self-management. 'Knowing what your limits are and getting to the point where…Whereas before you could just buy something and it could help. So you would buy a little gripper thing when I couldn't bend down… but that doesn't quite work all the time now… there are limits to what you can do' (Service-user 1).

Dependence on others

There was a sense from some service-users of how much they struggled with depending on others and how this can lead to feelings of hopelessness in regard to self-management: 'I hate other people doing things for me' (Service-user 6), 'I just wait until someone comes around…the other day I put that on the bottom (points to magazine on chair), it slid off onto the floor and there is no way of me picking it up' (Service-user 4).

Perception of Self & Disability

Defined by what I cannot do

Some service-users described a sense of hopelessness in what they were able to do now, 'I want to scream and run out and get in my car and drive off, but of course I can't do any of that. Because I don't drive and I can't get out and I don't know who to go to' (Service-user 5).

Defined by what I can do as well as what I cannot do.

A belief that many of the service-users held conveyed an approach of 'doing as much as they can', framing the things they were unable to do around the parts of life within which they were able to achieve what they wanted. 'I just, do as much as I can… I can wheel myself around in the wheelchair… and I like to answer the door… simple little things but important things for me to do' (Service-user 3).

And, 'There are some areas I can't conquer. Around the house I can conquer… so that is why I swim. So, I do try to manage it myself, I swim to keep this leg under control' (Service-user 6).

Furthermore the perceived benefits of self-management were evident in their self-efficacy, confidence and mastery they experienced. The identified achieved tasks weren't just related to service support but also within general problem solving, 'I suppose there is a feeling that you have done it yourself… and you have accomplished something' (Service-user 1).

It's who I am – pre-existing mind-set.

Many service-users reported their ability to self-manage was due to a pre-existing mind-set of being determined and perseverant. 'I think I always had it in me to be so positive' (Service-user 3) and 'I am a determined person' (Service-user 2).

Self-management of disability and personal values/interests.

There was an overwhelming sense of service-users describing their LTNC alongside their values: 'the most important thing is that I believe in God, [it] definitely keeps me going' (Service-user 3).

Service-users who reported a higher level of control over their condition acknowledged the importance of personal values/interests in maintaining a continued sense of who they were '… my wheelchair is in the hallway. I normally get straight in it and whizz down here and put all the shopping away. I do use it…I get around the garden in it, out the door and down the ramps. I can do the gardening on it' (Service-user 6).

'I do still make music. I used to play guitar… but I can't play that anymore but now I am doing stuff on the keyboard' (Service-user 4).

Role of non-professional support network.

Service-users conveyed a sense of more independent coping and self-managing when they and their support network were actively involved in their own care, i.e. sourcing information themselves and providing emotional support. 'We are looking at

me and my husband as a unit. No, we can do everything that I need to do' (Service-user 8).

Evaluation of Service Support

There was a variation reported amongst service-users in the quality of care received from different healthcare professionals.

Helpful Support Packages

Many service-users were complimentary about the package of care received, reporting it to be meeting their needs, confidence building and professionals to be "dedicated" to their roles, 'Package of everything is great. You know it just builds the confidence in someone like myself… For me it's all the things they have shown me' (Service-user 3) and 'I can't put a negative on anything really. They have all been smack on really' (Service-user 1).

Lack of Resources

Some service-users felt the physiotherapy provision was inadequate due to understaffing and long waits, 'I felt like I needed to be shown how to do more exercises or….somewhere to help me to try and gain some more strength in my legs' (Service-user 7).

'I think the service is in demand, under-staffed and can't cope. It can't give a proper service. And under the circumstances they do very well. Er it's just not enough and um yeh just not enough people in the team really' (Service-user 5).

Person-centred contact

Service-users conveyed how beneficial it was to have a service which was, on the whole, easy to make contact with. The service was described to be quick in responding in times of difficulties. Service-users valued the role of the service being there but not always being involved, and so allowing them to manage independently. 'Whenever [the service] have come and seen that I am struggling with something, I have had it almost immediately' (Service-user 6) and 'I think they have got it just about right. They leave me alone but they are there if I need them' (Service-user 7).

Service-users were pleased with how the service worked with other agencies, the expert knowledge provided and the flexible appointments given.

Some service-users did not consider the care received to be person-centred due to its focus on the things that could go wrong and they found that clinicians were responding to their needs based on people they have treated before and not thinking about their own presenting difficulties. In such circumstances, the service may have been taking a more objective and long-term approach to the service user's developing needs, and this can be challenging to individuals in the early stage of acceptance/managing the changes post diagnosis. '[Clinician] started talking about getting floor lifts in my house…I didn't want to hear it at that stage… But in a very negative way is that team all think about the worst scenario…They have probably seen so many different cases, different stages. And everybody has all said, well you are, when you are further down the road, as if there is absolutely no question that you are going to hit it at some stage' (Service-user 5).

Making decisions

Decision making was perceived by service-users to be generally collaborative, using a process of seeing what works for the individual with the clinician not necessarily taking an expert stance, 'I tend to make my own. So if I want to do something I will and if I don't I won't. I usually make the decisions and then run it by them and get their input' (Service-user 2).

In one instance a service-user noted uncertainty as to what decisions had been made and their role in these, 'I don't know because I don't know if decisions have been made' (Service-user 6).

Role of assistive devices provided by the service

Time taken to provide

There was variation described in service-users experience of the time taken to receive equipment, with some reporting it occurred quickly and others reporting it taking longer: 'It is mostly [the clinician] getting me the equipment, but it always takes a very long time' (Service-user 5).

Role in enabling/improving quality of life

Service-users perceived the equipment which the service had provided very beneficial in allowing them to do tasks and improve their quality of life, 'And [the clinician] is getting me a specialist sling made for the hoist' (Service-user 4).

Discussion

The themes that emerged from the interviews indicate the complexities and ambiguous nature of living with a LTNC. The data suggested that generally the service is providing high quality care and is perceived to be effective and with a beneficial impact on service-users. This study provides qualitative evidence that many of the principles from the *NHS Improvement Plan: Putting People at the Heart of Public Services* (Department of Health, 2004) are being adhered to, including: person-centred care, self-management support and provision of a comprehensive rehabilitation programme.

The diverse nature of the themes found indicate how important it is to consider self-management and its interaction with service users and their unique perspective of their condition. It underlines the importance of having quality standards such as the National Service Framework (Department of Health, 2005) to inform services of what level of care is expected.

Relationship of the findings to the literature

The themes found broadly illustrate areas found in previous research, for example it was evident there were generally good service-user clinician relationships, where respect and dignity were present, and this has also been noted by Peters et al. (2013). Additionally, in the current study, it was noted that service-users' comments suggest there may have been variable provision of information about their conditions and use of signposting to external organisations.

In the current study, there were two groups of individuals broadly evident. Firstly, service-users' who were primarily focused upon what they couldn't do and resultantly were perhaps slightly limited in their ability to self-manage or cope with their condition independently. Conversely, the second group were individuals who recognised similarly what they were unable to do but also showed recognition and appreciation for what they were able to do and the associated psychological benefits

of this. Furthermore, this second group of individuals presented as engaging more in pleasurable activities, with likely quality of life benefits. It is proposed this may be partly a consequence of having higher levels of self-efficacy in relation to their condition. These findings are in accordance with the Lazarus and Folkman's (1984) stress and coping model, as appraisals are known to influence psychological outcomes. It is possible that the group who had difficulties coping and self-managing may have increased intolerance of uncertainty compared to those who coped and self-managed more effectively (Freeston et al., 1994). Different techniques for supporting these groups may be necessary. Useful guidance on how professionals can support self-management is provided by Battersby et al. (2008), who identified three areas of self-management support skills for healthcare professionals to have to support the service users they work with : general person-centered skills, behaviour change skills and organisational system skills. It is recommended this could be adopted by the current service and other services in the form of skills training so as to enable and promote good practice.

Overall these findings provide a detailed description of the largely beneficial role the service provides in helping individuals to self-manage. However, difficulties were reported in certain areas such as with information provision and particularly how uncertainty is managed, signposting to other resources, and service waiting times.

Service development

Clinicians within the team were provided with a summary of these results. Recommendations were then derived based on discussion with the team, and consultation of the evidence-base on self-management.

The recommendations from the current study were as follows:

1) to develop self-management and signposting leaflets which define self-management and direct individuals where they can access further information/support. Within these leaflets service users would be signposted to external support agencies, such as passport to health or MS groups. In doing this it is hoped that awareness of other agencies that could provide support to the service user would increase.

2) to provide information leaflets at the initial visit regarding the service-user's LTNC, self-management and signposting to organisations which provide support.

3) To make all clinicians aware of the large impact that LTNCs can have on an individual's mental health and that this may be largely unseen by others.

4) To develop a service pathway in relation to self-management, detailing a clear process of reviewing self-management including intervention points whereby a stepped care approach is used, for example initially a clinician will offer self-management intervention, if this is deemed to not be successful then the service user will be referred to a self-management group.

5) For a screening questionnaire to be developed which can used by clinicians to help assess the level of self-management that is possible, and whether any further support needs to be provided. For clinicians to be made aware of the potential need to repeat information within the initial adjustment period and as the condition progresses.

6) To implement a GP awareness day where signposting information will be provided and education given.

7) For staff training on psychological management of LTNC to be developed that includes education on motivational interviewing, problem solving and how to maintain positivity in face of a LTNC.

8) For all clinicians to write a statement in the discharge summary clarifying the circumstances in which it would be appropriate to refer back to the service.

9) For all clinicians to be made aware of the importance of being clear regarding service role and expected time frame for provision.

10) Implementation of a service-user self-management group.

These recommendations may also be relevant to other CINHRTs.

Limitations and considerations

There are a number of limitations to this study. Despite defining what self-management is at the beginning of every interview, it was apparent that as a concept it has various definitions within the literature. There is a lack of clarity available in the literature as to the extent self-management is possible in those with severe physical disabilities who need the care and support of others on a daily basis. In the context of the current study, clinicians and participants may have perceived this concept differently and this may have influenced the responses given. A questionnaire could potentially provide more objective data in future research.

The eligibility criteria required participants to exhibit a level of self-management in order to participate. Consequently, this meant that service-users who didn't self-manage were unable to participate and the views of those service users who did not self-manage have not captured.

Use of qualitative methodology has provided a rich description of the experience of self-management in a small number of individuals. Despite this, as the number of service-users interviewed was low, we do not claim this is the service received by all, and ideally these data would be used in combination with data from routinely collected patient satisfaction measures.

Additionally, there was an overrepresentation of individuals with MS within the sample relative to other LTNCs, the results may not accurately reflect the experience of self-managing other conditions such as Parkinson's Disease.

Recommendations for future research

Future research that seeks to explore the experience of self-management in other LTNCs would be valuable. This would help in understanding whether it is most helpful to consider these conditions together or separately when thinking. Additionally, it would be of value to understand the barriers and facilitators of self-management. Future research also may be useful in exploring service-user's knowledge of self-management after provision of leaflets/education.

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Tables and Figures

Table 1. *Demographic and clinical information. Abbreviations: LTNC=long-term neurological condition, MS=multiple sclerosis, MND=motor neuron syndrome.*

[1]The Modified Rankin scale is a standardized scale (Bonita & Beaglehole, 1988) to measure degree of disability, rated in a 0-5 scale where 0=no disability and 5=severe disability, requires constant nursing care and attention.

[2]The Cognitive Scale was a custom scale for this study, rated 0-5 where 0=no impairment and 5=severe impairment

[3]The Self-Management Scale was a custom scale for this study, rated 0-5 where 0=no self-management and 5=high self-management

ID	M/F	Age	LTNC	Modified Rankin scale[1] (0:no disability– 5: severe)	Cognitive Rating[2] (0:none– 5: severe)	Self-management rating[3] (0: none – 5: high)	Level of support
S1	F	40s	MS	3.5	0	5	Independent
S2	M	40s	MND	2	0	4.5	Care Package
S3	M	50s	MS	4	2	2	Care Package
S4	M	50s	MS	4	2	3	Care package
S5	F	60s	MS	4	2	3	Carer, friends
S6	F	50s	MS	3	2	4	Husband, daughter
S7	F	50s	MS	4	0	3	Mother, husband
S8	M	50s	MS	3	2	2.5	Missing data
S9	F	30s	MS	3	1	2	Parents
Mean		-	-	3.38	1.22	3.22	-

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Table 2

Questions used to guide interviews

1) What has your experience been of the information the service has provided about your condition?
    a. How was information and support provided by the service about your condition?

2) How have you experienced how decisions have been made about your care?
    a. Who has made these?

3) What has your experience been of how the service has been in offering appointments to fit with your schedule?

4) In what ways do you manage your condition for yourself?
    a. How did you develop these strategies?
    b. How do you experience the benefits and/or challenges of self-managing your condition?
    c. What areas of your condition do you self-manage? What areas are you unable to self-manage, If not, why?
    d. When it is difficult to self-manage what do you do?
    e. Have you experienced any barriers to self-management?

5) How able or confident do you feel in self-managing your condition?
    a. Have you found any support helpful or not helpful?

6) Do you have any suggestions about what could be done better by the service to better help you to self-manage your condition?

Figure 1 Thematic Map